# Complete Summary

## GUIDELINE TITLE

Autistic spectrum disorders. Best practice guidelines for screening, diagnosis and assessment.

## BIBLIOGRAPHIC SOURCE(S)

California Department of Developmental Services. Autistic spectrum disorders. Best practice guidelines for screening, diagnosis and treatment. Sacramento (CA): California Department of Developmental Services; 2002. 183 p. [220 references]

## GUIDELINE STATUS

This is the current release of the guideline.

## COMPLETE SUMMARY CONTENT



## SCOPE

### DISEASE/CONDITION(S)

Autistic spectrum disorders (ASD), including autistic disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS), and Asperger's disorder

Note: Rett's disorder and childhood disintegrative disorder (CDD) were excluded.

### GUIDELINE CATEGORY

Diagnosis
Evaluation
Screening

## CLINICAL SPECIALTY

Family Practice
Neurology
Pediatrics

## INTENDED USERS

Advanced Practice Nurses
Nurses
Physicians
Psychologists/Non-physician Behavioral Health Clinicians

## GUIDELINE OBJECTIVE(S)

- To provide professionals, policymakers, parents and other stakeholders with recommendations based on published research, clinical experience and judgment available about "best practice" for screening, evaluating and assessing persons suspected of having autistic spectrum disorder (ASD)
- To increase education and awareness of ASD among the public and policy-makers and provide a basis for training to achieve the high quality clinical screening and diagnostic skills anticipated

## TARGET POPULATION

Individuals from birth through age 22

## INTERVENTIONS AND PRACTICES CONSIDERED

### Screening, Diagnosis, and Evaluation

Birth Through Age Five

1. Screening for autistic spectrum disorders (ASD)
    - Use of screening instruments for general development and ASD
    - Referral of a child with possible ASD
2. Diagnostic evaluation
    - Role of clinicians and agencies in the diagnostic evaluation process
    - Role of the diagnostic environment
    - Components of a best practice diagnostic process
        - Review of relevant background information
        - Parent/caregiver interview
        - Medical evaluation
        - Direct behavior observation
        - Cognitive assessment
        - Assessment of adaptive functioning
    - Formulating conclusions and presenting information on the diagnostic evaluation

3. Assessment for intervention planning
    - Assessment of communication: speech and language

- Assessment of motor skills and sensory processing
- Assessment of behavioral functioning
- Assessment of adaptive functioning
- Assessment of family functioning and coping resources

4. Formulation, presentation, and documentation of findings

Age Six and Older

1. Consideration of issues and concepts in referral, diagnostic evaluation, and assessment
2. Referral considerations
3. Components of a diagnostic evaluation/assessment process
    - Diagnoses in older children and adolescents
    - Primary components
        - Record review
        - Medical evaluation
        - Parent/caregiver interview
        - Direct child evaluation
        - Psychological evaluation
        - Communication assessment
        - Evaluation of social competence and functioning
        - Evaluation of restricted patterns of behavior, interests and activities
        - Assessment of family functioning
    - Secondary components
        - Evaluation of academic achievement
        - Neuropsychological assessment

4. Differential diagnosis
5. Elements of diagnostic formulation, presentation and documentation

MAJOR OUTCOMES CONSIDERED

Sensitivity and specificity of screening and diagnostic tests

## METHODOLOGY

METHODS USED TO COLLECT/SELECT EVIDENCE

Searches of Electronic Databases

DESCRIPTION OF METHODS USED TO COLLECT/SELECT THE EVIDENCE

Not stated

NUMBER OF SOURCE DOCUMENTS

Not stated

## METHODS USED TO ASSESS THE QUALITY AND STRENGTH OF THE EVIDENCE

Not stated

## RATING SCHEME FOR THE STRENGTH OF THE EVIDENCE

Not applicable

## METHODS USED TO ANALYZE THE EVIDENCE

Review

## DESCRIPTION OF THE METHODS USED TO ANALYZE THE EVIDENCE

Not stated

## METHODS USED TO FORMULATE THE RECOMMENDATIONS

Expert Consensus

## DESCRIPTION OF METHODS USED TO FORMULATE THE RECOMMENDATIONS

In July 2001, the Department of Developmental Services (DDS) launched an Autistic Spectrum Disorder Initiative with the following goals: to establish policy and best practice in assessment and intervention, and to establish public and private partnerships to address the needs of persons with autistic spectrum disorders (ASD). Completion of these Guidelines represents one of the first steps of the initiative. To assist with the ASD Initiative, a Director's Advisory Committee on ASD was formed (See Appendix M of the original guideline document for a full listing of Advisory Committee Members). This committee consists of professionals and parents with recognized commitment to best practices in ASD who advise DDS on program and policy issues pertaining to autism.

At the same time, related events were occurring within DDS and in the professional community at-large. In April 2001, work began on a DDS Wellness grant awarded to Valley Mountain Regional Center and Children's Hospital Oakland to promote clinical excellence in diagnosis and intervention services for young children with ASD. The goals of the grant were to convene an interdisciplinary panel; draft guidelines for the screening, diagnosis, and assessment of ASD in children from birth to 5 years of age; and begin training of regional health care providers. Similarly, the Association of Regional Center Agencies (ARCA) Eligibility Committee had been meeting to gain consensus on guidelines for diagnosing, assessing, and establishing service eligibility for ASD.

The California State Legislature gave direction for developing evaluation guidelines in August 2001. Responding to the 1999 report from DDS and to concerns of parents and the professional community, the Legislature passed Assembly Bill 430, acknowledging the need for "the same diagnostic tools and...the same

diagnostic methods...to ensure consistency and accuracy of diagnosis of autism disorder and other pervasive developmental disorders throughout California."

Finally, several national consensus panels have published evidenced-based guidelines for screening, diagnosis, and assessment of ASD. These Guidelines build on the work of the aforementioned groups within California and the best practice foundation laid by other organizations.

### RATING SCHEME FOR THE STRENGTH OF THE RECOMMENDATIONS

Not applicable

### COST ANALYSIS

A formal cost analysis was not performed and published cost analyses were not reviewed.

### METHOD OF GUIDELINE VALIDATION

Peer Review

### DESCRIPTION OF METHOD OF GUIDELINE VALIDATION

Not stated

## RECOMMENDATIONS

### MAJOR RECOMMENDATIONS

Screening for Autistic Spectrum Disorders (ASD)

Age 0 to 5

All professionals responsible for the care of children perform routine developmental surveillance to identify children with atypical development.

All professionals involved in the care of young children are aware of developmental indicators of ASD.

Specific screening for ASD occurs for all children at 18 and/or 24 months of age.

Parents' concerns about their child's development and behaviors are elicited at every health care provider contact, including well- and ill-child visits.

A regional interagency training and information sharing process is in place to assure early identification of persons with ASD.

Healthcare professionals stay up-to-date on best practice guidelines and related research.

Specific screening between 18 and 24 months for ASD includes the Modified Checklist for Autism in Toddlers (M-CHAT) or the Pervasive Developmental Disorder Screening Test-II (PDDST II) or other approved instrument.

Primary care providers have access to an up-to-date resource directory that facilitates the referral process of children and adolescents to a clinical team that specializes in diagnosing ASD.

Within the constraints of confidentiality, efficient sharing of information among clinicians assures timely referral and more complete evaluation of children for concerns regarding ASD.

Diagnostic Evaluation

Age 0 to 5

The diagnosis of ASD should be made as soon as possible to facilitate intervention and initiate family counseling.

All clinical team members are familiar with and are able to recognize the child's developmental level and behaviors that correspond to the diagnostic criteria for ASD in young children.

Because symptoms change over time, a young child with an early diagnosis of ASD should be reexamined at least annually to confirm the diagnosis and plan treatment.

To enable intervention as soon as possible, the diagnostic evaluation is efficiently organized and coordinated.

The diagnostic evaluation includes examination of multiple domains of functioning to differentiate ASD from other conditions and provides a complete profile of the individual to allow for comprehensive intervention planning and service initiation.

Planning for diagnostic evaluation before meeting with the child and family includes identifying and reviewing all sources of relevant background information, selection of tests including alternative test procedures, and identifying opportunities for informal observation that can supplement formal assessment procedures.

An interdisciplinary team is the preferred method for conducting a comprehensive diagnostic evaluation. In the absence of the interdisciplinary team, a single clinician with specialist training and experience in evaluating ASD in young children can make a diagnosis.

The primary health care provider is involved with other professionals in the diagnosis and treatment of a child with ASD, and assists and coordinates specialty care and referrals.

Informed clinical judgment is maintained through periodic training that includes case review, peer review of individual cases, and discussion of published literature.

When clinically indicated, observations of a child in various settings and at different times increases the validity of information obtained and assists in diagnosis, case management, and intervention.

The evaluative process begins with a review of all sources of relevant background information. Attempts should be made to gather as much of this information as possible before the meeting with the child and family.

Diagnostic accuracy improves when the diagnostic team uses formal diagnostic tools, clinical experience, and clinical judgment in diagnosing children suspected of ASD.

A comprehensive medical assessment including health history, physical examination, and developmental/neurological examination is performed as part of the diagnostic evaluation.

All children as part of their developmental assessment are screened for vision and hearing with referral to specialists as appropriate.

Direct behavior observation of the child in both structured and unstructured settings improves the accuracy of the diagnosis of ASD.

Evaluation of cognitive functioning in both verbal and nonverbal domains is a necessary component of the complete diagnostic profile of the child. Developmental levels and/or informal measures are used when formal measures are inappropriate.

Domains of adaptive function are evaluated for all children, as they are pivotal in diagnosing ASD and/or coexisting mental retardation.

Assessment for Intervention Planning

Age 0 to 5

Ongoing assessment of a child's behavior and developmental profile is maintained in order to reformulate assessment conclusions and plan appropriate intervention.

The involvement of parents is essential in the assessment process as they are most knowledgeable regarding the child.

Cultural and family values are considered throughout the assessment process, as they will guide team recommendations and intervention planning.

The setting in which the child is evaluated, i.e., office, home, or childcare facility, is carefully chosen to obtain representative information regarding development and behavior.

Although all domains must be explored for each child, the interdisciplinary team tailors in-depth assessments to the unique needs of each child and his or her family.

## Formulation, Presentation, and Documentation of Findings

### Age 0 to 5

The final diagnostic formulation derives from using clinical judgment to integrate clinical data with Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV/International Classification of Diseases (ICD)-9 diagnostic criteria.

Presentation of the diagnosis to family members is accomplished by those clinicians or team members best able to communicate a comprehensive understanding of the child and support parents during the discussion.

Written reports document diagnostic conclusions keyed to specific DSM-IV criteria. Evaluation and assessment reports are comprehensible to parents and providers and contain practical recommendations for the next phase in the process.

## Issues and Concepts in Referral, Diagnostic Evaluation, and Assessment

### Age 6+

Referring parties are provided with detailed information regarding evaluation resources in order to streamline the referral process and minimize delays and stress for children, families, and providers alike.

The interdisciplinary team is preferred for diagnostic evaluation and intervention planning for older children and adolescents, as they may require a broad range of assessment procedures.

Differential diagnosis necessitates careful attention to clinical features consistent with both ASD as well as other disorders of childhood that have overlapping and coexisting symptoms.

Accurate identification and description of coexisting psychiatric conditions and consequent symptoms establishes the basis for quality intervention planning.

An accurate and detailed family medical/psychiatric history and review of psychosocial factors, which may play a role in clinical symptom expression, is essential in the diagnostic process for the older child and adolescent.

The collation and integration of multiple sources of information strengthens the reliability of the diagnosis; conclusions are weighted with respect to all evidence.

The developmental disability and mental health service systems collaborate and cooperate to be effective in addressing the unique service needs of children with ASD.

An assessment for intervention planning in older children includes an evaluation of skills and competencies required for transitions, such as the transition from elementary to middle school or from home to residential living.

Assessment protocols should be designed to assist in development of functional curricular goals and intervention strategies that take advantage of the child's demonstrated skills and learning style.

Referral Process

Age 6+

Referring parties clearly identify the reason for referral, select the most appropriate evaluation resource, and share relevant information in a timely manner.

Components of a Diagnostic Evaluation/Assessment Process

Age 6+

Accuracy of assessment of older children and adolescents with adequate language skills requires a face-to-face interview.

When the evaluation and assessment requires differential diagnosis of psychiatric disorders, the clinician seeks further referral and/or consultation when indicated.

Because of wide variability in the expression of language ability among children and adolescents, a thorough communication assessment is a necessary component of the diagnostic evaluation.

Evaluation of academic achievement is included in intervention planning when learning, behavioral, or psychiatric disorders are suspected of playing a role in the older child's or adolescent's symptom presentation.

### CLINICAL ALGORITHM(S)

None provided

## EVIDENCE SUPPORTING THE RECOMMENDATIONS

### TYPE OF EVIDENCE SUPPORTING THE RECOMMENDATIONS

The type of evidence supporting the recommendations is not specifically stated.

## BENEFITS/HARMS OF IMPLEMENTING THE GUIDELINE RECOMMENDATIONS

### POTENTIAL BENEFITS

Early diagnosis of autistic spectrum disorders in children and improved outcomes due to appropriate and early intervention

### POTENTIAL HARMS

Not stated

## QUALIFYING STATEMENTS

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Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment provides recommendations, guidance, and information about current "best practice" in the field. These Guidelines offer evidence-based recommendations and cannot be interpreted as policy or regulation, but as a tool designed to help health care providers and families make informed decisions regarding identification, diagnosis and assessment of autistic spectrum disorders (ASD). Additionally, these Guidelines provide a framework for the development and broad implementation of educational and training programs designed to reach professionals who in their day-to-day practice may encounter individuals suspected of having an ASD.

## IMPLEMENTATION OF THE GUIDELINE

### DESCRIPTION OF IMPLEMENTATION STRATEGY

An implementation strategy was not provided.

### IMPLEMENTATION TOOLS

Chart Documentation/Checklists/Forms
Foreign Language Translations
Quick Reference Guides/Physician Guides

For information about availability, see the "Availability of Companion Documents" and "Patient Resources" fields below.

## INSTITUTE OF MEDICINE (IOM) NATIONAL HEALTHCARE QUALITY REPORT CATEGORIES

### IOM CARE NEED

Living with Illness
Staying Healthy

### IOM DOMAIN

Effectiveness
Patient-centeredness

## IDENTIFYING INFORMATION AND AVAILABILITY

### BIBLIOGRAPHIC SOURCE(S)

California Department of Developmental Services. Autistic spectrum disorders. Best practice guidelines for screening, diagnosis and treatment. Sacramento (CA): California Department of Developmental Services; 2002. 183 p. [220 references]

### ADAPTATION

Not applicable: The guideline was not adapted from another source.

### DATE RELEASED

2002

### GUIDELINE DEVELOPER(S)

California Department of Developmental Services - State/Local Government Agency [U.S.]

### SOURCE(S) OF FUNDING

California Department of Developmental Services

### GUIDELINE COMMITTEE

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## FINANCIAL DISCLOSURES/CONFLICTS OF INTEREST

Not stated

## GUIDELINE STATUS

This is the current release of the guideline.

## GUIDELINE AVAILABILITY

Electronic copies: Available in Portable Document Format (PDF) from the California Department of Developmental Services Web site.

Print copies: Available from the California Department of Developmental Services, 1600 Ninth Street, Room 330, MS 3-8, Sacramento, CA 95814

## AVAILABILITY OF COMPANION DOCUMENTS

The following is available:

- California Department of Developmental Services. Quick reference guide for autistic spectrum disorders. Best practice guidelines for screening, diagnosis and assessment. Sacramento (CA): California Department of Developmental Services; 2003. 41 p. Available in Portable Document Format (PDF) from the California Department of Developmental Services Web site.

Print copies: Available from the California Department of Developmental Services, 1600 Ninth Street, Room 330, MS 3-8, Sacramento, CA 95814

The following are also available:

- Modified checklist for autism in toddlers (MCHAT). Appendix C. Autistic spectrum disorders. Best practice guidelines for screening, diagnosis and treatment. Sacramento (CA): California Department of Developmental Services; 2002. Electronic copies: Available in Portable Document Format (PDF) from the California Department of Developmental Services Web site.
- Modified checklist for autism in toddlers (MCHAT) Spanish. Appendix D. Autistic spectrum disorders. Best practice guidelines for screening, diagnosis and treatment. Sacramento (CA): California Department of Developmental Services; 2002. Electronic copies: Available in Portable Document Format (PDF) from the California Department of Developmental Services Web site.
- Pervasive developmental disorder screening test-II. Appendix E. Autistic spectrum disorders. Best practice guidelines for screening, diagnosis and treatment. Sacramento (CA): California Department of Developmental Services; 2002. Electronic copies: Available in Portable Document Format (PDF) from the California Department of Developmental Services Web site.

### PATIENT RESOURCES

None available

### NGC STATUS

This NGC summary was completed by ECRI on January 10, 2006. The information was verified by the guideline developer on February 9, 2006.

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